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Misclassification of American Indian Race in Cancer Incidence Data in North Carolina

by

Karen Knight, M.S.
Bonnie C. Yankaskas, Ph.D.
Anthony Fleg, M.P.H.
Chandrika Rao, Ph.D.

Abstract

Objectives: The purpose of this study is to quantify the extent of misclassification of race among non-federally recognized American Indians in North Carolina cancer incidence data, correct race among those misclassified, and evaluate the impact of misclassification on American Indian cancer incidence rates.

Methods: We identified 14 counties in North Carolina that had the majority of American Indians belonging to the seven state-recognized, non-federally recognized tribes. We collaborated with the tribe in each county and matched the cases of cancer in the North Carolina Central Cancer Registry (CCR) to the tribal rolls. Data were analyzed to calculate what percentage of matching names were not correctly identified as American Indian in the CCR. We calculated the percentage misclassified, corrected the CCR classification, and then recalculated the cancer incidence rates for total cancer and four major cancers (prostate, female breast, lung, and colorectal). We compared the recalculated rates to the original rates.

Results: There were 626 American Indians listed on the tribal rolls who matched to the CCR case records; 112 (17.9%) were not identified as American Indian on the CCR list. Comparing 1996–2000 age-adjusted cancer incidence rates before and after reclassification, the increase in rates for American Indians was 19 percent for all cancers, 41 percent for prostate, 18 percent for female breast, 10 percent for lung, and 11 percent for colorectal cancer.

Conclusions: The study estimated 18 percent under-ascertainment of non-reservation American Indians in cancer registration in North Carolina. The underestimation of cancer burden among American Indians in North Carolina may lead to lower resources for prevention, screening, and treatment programs, as well as lower funding for research.

Note about the authors: Karen Knight and Chandrika Rao work at the State Center for Health Statistics. Bonnie Yankaskas and Anthony Fleg work in the Department of Radiology, University of North Carolina at Chapel Hill.



North Carolina Department of Health and Human Services

Introduction

Equitable distribution of health care resources requires accurate morbidity and mortality data for all racial and ethnic subgroups of the population. Medical records or other non-primary sources of racial or ethnic identification may be prone to higher errors than information collected directly from the individual. Many studies have shown that for American Indians and Alaska Natives in particular, there is a large amount of misclassification on death certificates and in other disease surveillance systems. Several studies compared death certificates to Census data, Indian Health Service (IHS) records, or tribal registries to assess accuracy of mortality statistics.¹⁻⁶ A few compared death certificates to disease-specific registries where race and ethnicity were reported directly from the patient to assess accuracy of disease incidence statistics.⁷⁻¹² Some studies used national data,^{1,4} while others used state or regional data.^{2,3,6-11} One study compared Veterans Affairs self-reported race to an administrative database.¹³ All these studies found varying rates of misclassification of American Indians as non-American Indian, with misclassification rates varying from a low of 9 percent to a high of 96 percent. Misclassification increased as the percentage of American Indian “blood quantum” decreased.^{2,6,8}

Evidence of misclassification has been documented in North Carolina as well. The North Carolina Central Cancer Registry (CCR) submitted its 1995–2005 incidence data to the IHS and 21 percent of those identified as American Indian by the IHS were identified as a different race in the cancer incidence records. Similarly, a linkage between North Carolina death certificates and the IHS data suggested a 17 percent underreporting of American Indian race on North Carolina death certificates.⁶ This pervasive misclassification of American Indians may result in substantially underestimated mortality and morbidity rates for American Indians in North Carolina.

The studies cited above mostly relied on IHS data to estimate misclassification rates of mortality and morbidity. These data include patient records for federally recognized American Indian tribes

covered by the IHS, which cannot necessarily be generalized to regions such as the southeastern United States, where the majority of the American Indians are not federally recognized and not served by the IHS. North Carolina has the largest population of state-recognized, non-federally recognized American Indians in the United States.¹⁴

The objective of this study is to evaluate the accuracy of classification of American Indians in North Carolina’s cancer incidence records, and to estimate the effect on reported cancer incidence in North Carolina, where the majority of American Indians are not associated with federally recognized tribes.

Methods

Data Sources

We estimated misclassification rates of race in the CCR for American Indians in North Carolina. We matched cancer cases from the CCR to tribal rolls for seven non-reservation Indian tribes in North Carolina: Coharie, Haliwa-Saponi, Lumbee, Meherrin, Occaneechi Band of Saponi Nation, Sappony, and Waccamaw-Siouan. To test if American Indian cancer records in the CCR are correctly classified as American Indian, all cancer records for the main counties in which each tribe resides were matched to the tribal rolls. For those records that did match to the tribal rolls, we determined if the race was classified as American Indian in the CCR. This project was developed through a partnership between the CCR, the Carolina Mammography Registry (CMR), and the North Carolina Commission of Indian Affairs (NCCIA) with assistance from health outreach coordinators and tribal enrollment officers who were critical to the collection of data.

IRB Approval

Approval was obtained from the North Carolina Division of Public Health Institutional Review Board (IRB) as well as the University of North Carolina School of Medicine IRB. All personnel were trained on Health Insurance Portability and Accountability Act (HIPAA) rules and rules of confidentiality.

Identification of Study Group

There are seven state-recognized tribes in North Carolina that are not federally recognized and thus do not use the IHS. An American Indian research assistant met with each tribe to explain the project and request collaboration with us on this project. A few of the tribes kept their tribal rolls in electronic format. Most of the tribes were reluctant to release their tribal rolls to someone who is not a member of the tribe. Therefore, each tribe identified someone to work on the project and conduct manual linkage. Because the linkage was manual, a county or counties where the majority of tribal members resided were identified, and the study was limited to these counties. The CCR produced a list of all persons with any type of cancer who resided in the identified counties. We provided this list to the tribes for them to match to their tribal rolls. The tribal populations as a percentage of all North Carolina American Indians and the primary counties included in this study are shown in Table 1.

Data Collection

The linkage of the CCR names to the tribal rolls was performed by a member of the tribe, at the tribal location. The research assistant met with each tribe separately to provide training for the project. A training video was created and presented to each tribe, using a representative of the NCCIA and the CCR as trainers. Once a tribal staff member was

identified to work on the research, HIPAA training was completed through the University of North Carolina and a signed confidentiality agreement was kept on file at the CCR.

The list generated by the CCR included all cancer cases diagnosed from 1996 through 2002, as well as some non-cancer death records randomly mixed in to help mask which individuals had cancer. The list included last name, first name, middle name, date of birth, and the last four digits of the patient's Social Security Number. The last known address was included for verification of matches. The list did not include the race classification. All names on the CCR list were searched for in the tribal roll. If a name on the CCR list was found in the tribal listing, the name was highlighted on the CCR list. All tribal rolls were produced as paper lists, some from computerized listings and some from paper records, and the research assistant manually matched the two paper lists. Once the matching process was completed, the highlighted CCR list was sent back to the CCR.

Data Analysis

We calculated the percentage of cancer records that matched to the tribal rolls that were not previously identified as American Indian in the CCR database. Prior to the project, we calculated age-adjusted incidence rates for female breast, prostate, lung, colorectal, and total cancers diagnosed during the

Table 1. North Carolina Tribes Included in Study with Percentage of All North Carolina American Indians and Primary Counties Included in Study

Tribe	% of All North Carolina American Indians	Counties Included in Study
Lumbee	54.2%	Robeson, Scotland, Hoke
Haliwa-Saponi	3.2%	Halifax, Warren, Nash
Waccamaw-Siouan	2.4%	Columbus, Bladen
Coharie	1.9%	Harnett, Sampson
Occaneechi Band of Saponi Nation	0.9%	Alamance, Orange
Meherrin	0.8%	Hertford
Sappony	0.2%	Person

Table 2. Misclassification of American Indian Race in the CCR, by Tribe

Tribe	Number of CCR Records Matching to Tribal Rolls	Subset with American Indian Race Not Recorded in the CCR	Percent Misclassified
Lumbee	554	86	15.5%
Haliwa-Saponi	20	3	15.0%
Waccamaw-Siouan	23	10	43.5%
Coharie	16	2	12.5%
Occaneechi	9	8	88.9%
Meherrin	2	2	100.0%
Sappony	2	1	50.0%
Total	626	112	17.9%

Caution: All of the percentages by tribe except the one for Robeson are based on small numbers and thus may be statistically unstable.

period 1996 through 2000 for American Indians in the 14 counties. These sites were chosen because they have the highest numbers of cases and thus provide more stable incidence rates. The years 1996–2000 were chosen because data from the 2000 diagnosis year was the most current diagnosis year available at the time of the study. After completion of the project, these rates were re-calculated to demonstrate the impact on the incidence rates of correcting American Indian race.

To compare changes for other racial groups, we also recalculated rates for white and African American populations in the 14 counties where the study was conducted. Because the CCR database is updated continually, some of the changes from before to after the project could be due to new cases reported from previous years.

Results

There were 99,941 American Indians in North Carolina according to the 2000 Census. The number of persons on the tribal rolls of the seven tribes included in this study was 63,562, representing 64 percent of all American Indians in

North Carolina¹⁵ (Table 1). When the tribal rolls were matched to the CCR list of cancer cases with residence in the 14 study counties, we found 626 American Indians on the tribal rolls who were on the CCR list of cancer cases. Of these 626, 112 (17.9%) were not identified as American Indian in the CCR database list. The results by tribe are shown in Table 2.

The American Indian cancer incidence rates for 1996–2000 increased after correction of race. For all cancers combined, there was an increase of 19 percent (285.8 to 341.4). Cancer incidence rates in American Indians rose 41 percent for prostate, 18 percent for female breast, 10 percent for lung, and 11 percent for colorectal cancer (Table 3). For all cancers combined, the increase in the incidence rates for whites and African Americans was 2 percent. The small increase in rates for whites and African Americans is due to updated reporting of cancer cases since the original rate calculations.

There were a number of persons on the CCR list for the 14 counties who were identified as American Indian in the cancer records but were not listed on the tribal rolls. This may be explained

by several factors: 1) there are American Indian tribal members who are not listed on the tribal rolls; 2) there are American Indians living in North Carolina who are members of tribes other than the seven state-recognized tribes, including the Eastern Band of Cherokee; and 3) there are members of these tribes who belong to the American Indian Associations in urban areas and thus are not listed on the tribal rolls.

Discussion

This study documented a substantial misclassification of non-reservation American Indians in cancer registration in North Carolina. We found that 18 percent of cancer cases listed on American Indian tribal rolls were not classified as American Indian in the CCR. For all cancers combined, the cancer incidence rate for American Indians increased by 19 percent after correcting the data for misclassification.

There is published evidence that American Indians are particularly susceptible to misclassification in health data, which has proven to be true in North Carolina for both cancer incidence records and death certificates. Annual linkages between these data and IHS patient records helps correct for misclassification for those served by the IHS (only

the Eastern Band of Cherokee in North Carolina), but we have been lacking an accurate picture of the cancer burden for all American Indians, particularly those not served by the IHS. After correction of rates based on linkages with the IHS data, age-adjusted cancer incidence rates among American Indians are still consistently lower than those for whites and African Americans in North Carolina.

The same pattern of lower cancer incidence rates for American Indians is seen nationally. In the 1975–2004 annual report to the nation, prepared by collaboration between the American Cancer Society, the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries, and the National Cancer Institute, there is a special comprehensive presentation of cancer information for American Indians and Alaska Natives (AI/AN). The average annual age-adjusted incidence rate of all cancers in the AI/AN male population between 1999–2004 was 406.9 per 100,000 persons, lower than that for African American and white males, (635.1 and 549.7 respectively).⁵ These findings are consistent with the most recent annual American Cancer Society data and earlier data from Surveillance, Epidemiology, and End Results (SEER) program.^{12,16}

Table 3. Comparison of 1996–2000 Cancer Incidence Rates* (Per 100,000 Population) Before and After Correction of Misclassification

Cancer Site	Before Correction						After Correction					
	White		African American		American Indian		White		African American		American Indian	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
Colon/Rectum	1,496	51.6	583	53.7	46	20.5	1,492	51.4	584	53.9	50	22.7
Lung/Bronchus	2,164	73.1	684	62.4	113	52.5	2,193	74.1	682	62.3	124	57.6
Female Breast	2,327	148.5	827	129.6	118	91.5	2,291	146.0	830	129.9	139	107.6
Prostate	1,651	131.4	907	210.6	120	131.2	1,664	133.1	957	222.7	162	186.1
All Cancers	12,707	435.9	4,858	440.3	635	285.8	12,917	443.2	4,932	447.4	752	341.4

* Rates are calculated for the counties of Alamance, Bladen, Columbus, Halifax, Harnett, Hertford, Hoke, Nash, Orange, Person, Robeson, Sampson, Scotland, and Warren, and are age adjusted to the 2000 United States Census population.

For non-reservation Indians not receiving health care from the IHS, there is greater opportunity for misclassification, since they receive their care in community settings along with patients who are not American Indian. It is possible that for cancer, in particular, misclassification might be a larger problem, since the cancer diagnosis that is reported to the CCR is often the result of a surgical or radiological visit, and less often reported from a primary care visit for the patient. The specialist physician may not know the patient as well and may not ask the patient to self-report race.

The results of this study indicate the need for better reporting and recording of racial identity by the health care system. American Indians should be encouraged to actively request that their race be put in their medical records when receiving medical services. We suggest that, especially for communities where American Indians reside in appreciable numbers, primary care practices and emergency room staff be encouraged to always ask the patient for racial or ethnic identity, and make sure this information is accurately recorded in the medical record. It is probably not feasible to regularly match cancer registry records to tribal rolls, since few tribal rolls are kept in electronic format, and many tribes are not willing to release their rolls for this purpose.

There are some limitations to consider when interpreting our results. Although we included all non-reservation tribes in the project, we matched only for 14 counties where there was a large number of American Indians for the seven tribes, and not for all American Indians in the state. So the results cannot be generalized statewide. It is possible that there was human error in the matching process, such that the representative said a name matched their tribal rolls when indeed it did not, or that the representative said a name did not match their tribal rolls when it did. The degree of this type of error is unknown.

There were names identified as American Indian on the CCR list that were not on the tribal rolls. Thus, the population indicated as American Indian, but not currently registered with a tribe, is not included in our misclassification rates. These include mostly American Indians residing in North

Carolina who are members of out-of-state tribes, the Eastern Band of Cherokee, or belong to tribes not recognized by the state.

Our study is the first to match tribal rolls to cancer registry data in an American Indian population that is not served by the IHS. Our results document that there is substantial under-identification of American Indians in cancer registration in North Carolina for non-reservation Indians. Race is usually reported at the time that medical services are provided. Other than special linkage projects such as this one, the solution to better reporting of race lies in correctly identifying race at the point of medical services, usually upon intake at a medical facility. For American Indians to receive the benefit of research, medical care, and education about cancer, we must accurately document cancer incidence and mortality in this population.

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